

# Using Discord in the Community, and Other Means of Online Collective Trans Care: Decision-making and Storytelling in Online Transgender Health Support Groups

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For many transmasculine and nonbinary people, the decision about whether to have a gender-affirming surgery known as “top surgery” is an important part of gender transition. To examine how online support communities may influence top surgery decision-making, we conducted four online asynchronous focus groups ( $N = 21$ ) using Facebook and Discord. As we show, different factors (including societal expectations and participants’ race, disability status, and gender) can influence both decision-making and the ways that people seek support; the research spaces themselves—the focus groups on Discord and Facebook—became supportive environments that helped with participants’ decision-making, and many participants eventually sought top surgery using non-traditional approaches that

they had learned more about in these (and other) online communities. We discuss how top surgery-related online support communities can facilitate trans care. We also discuss the many types of storytelling that participants engaged in in these spaces—one of the key elements, we posit, of participants' decision-making. Finally, we provide recommendations for future researchers, discussing how focus group composition impacts intracommunity dynamics and how Discord can be used to facilitate online focus groups.

**KEYWORDS** transgender identity; health and wellbeing; online focus groups; top surgery; Discord  
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Online communities and spaces are important for LGBTQ+ people broadly, and trans people specifically, because they enable social support, identity affirmation, information seeking and sharing, education, development of community knowledge, and recognition of shared experiences (Craig et al. 2021; Cipolletta, Votadoro, and Faccio 2017; Dowers, Kingsley, and White 2021; B. Miller 2017; Prinsloo 2011; Rawson 2014; Selkie et al. 2020). Trans people often turn to online community spaces for health-related information and support exchange for several reasons: the current anti-trans political climate, as well as a long history of medical gatekeeping, trans exclusion in mainstream healthcare systems, and disregard for trans expertise about trans bodies (shuster 2021). Online spaces can help fulfill trans people's unique health and transition needs (Chuanromanee and Metoyer 2021; Hawkins and Giesecking 2017; Prinsloo 2011). In online communities, trans people can find meaningful information (Cannon et al. 2017; Huttunen and Kortelainen 2021) and feel safe to share about their own experiences (Cipolletta, Votadoro, and Faccio 2017; Hawkins and Haimson 2018) through storytelling, which can help them and others make sense of gender transition and its dominant narratives (Horak 2014). Previous work on online support spaces has examined online identity formation, intra-community dynamics, and the benefits and harms that can arise in online LGBTQ+ support groups (Scheuerman, Branham, and Hamidi 2018; Walker and DeVito 2020).

Transmasculine and nonbinary “top surgery” is often a part of gender transition for assigned-female-at-birth transmasculine and nonbinary people; it is a medically necessary gender-affirming procedure that removes breast tissue to produce a flat chest (Bluebond-Langner et al. 2017; Nolan et al. 2020; Wilson et al. 2018). This is a common, safe outpatient surgery (Bluebond-Langner et al. 2017) that substantially increases quality of life and mental health and decreases gender dysphoria for many transmasculine and nonbinary people (Nolan et al. 2020; Poudrier et al. 2019; Puckett et al. 2018).

Past work in transgender studies has challenged traditional views of gender transition (Rachlin 2018) such as the linear narrative and examined gender confirmation surgery from different perspectives (Heyes and Latham 2018), but these findings have not yet been empirically examined in relation to trans people's use of technology or to their expressed needs. To address this gap, we pose the following research questions:

**RQ1:** What is the role of online support groups for decision-making in surgery? How do participants use information found from these groups?

**RQ2:** What kinds of surgery-related decisions do participants discuss in online support groups? To what extent does active and passive participation in these groups impact the decision being made?

**RQ3:** How does the choice of platform (e.g., Facebook, Discord) influence focus group dynamics in asynchronous online focus groups? How can a platform's affordances affect group member interactions and support?

To explore these questions, we conducted four asynchronous focus groups with  $N = 21$  participants using Discord and Facebook. We collected qualitative data on online support groups' role in decision-making and in identity formation and understanding via storytelling. We found that while participants gathered a variety of helpful information inside and outside of online support groups, the stories told through these groups were invaluable in influencing participants' decision-making and their thoughts about themselves and their transitions. We also observed that focus group participants demonstrated trans care and collective self-care (Malatino 2020) within the groups. We did find some differences in the focus groups on Discord and those on Facebook; these differences indicate that Discord may be the more appropriate platform for facilitating focus groups on trans-related topics.

## RELATED WORK

To understand how online communities can support people considering top surgery, we must first understand how trans people's decision-making about surgery is shaped by their access to care—both medical care and care from their communities. Top surgery is a common surgery pursued by many transmasculine and assigned-female-at-birth nonbinary people (Bluebond-Langner et al. 2017; Wilson et al. 2018), but access to top surgery is often limited. Historically, surgery candidates were evaluated based on how well they performed their desired gender and how closely the personal narrative they provided matched with doctors' conceptions of what trans narratives should include: binary gender identities, heterosexuality, and stories of being “trapped in the wrong body” (Denny 2004; Stone 2013). Similar gatekeeping and harmful expectations surrounding trans narratives continue today (Lau and Kwok 2009; Pitts-Taylor 2020). The former “transsexual model,” which posited trans identity as a mental illness that could be cured by medical procedures, has been replaced by the newer “transgender model,” which views medical options like surgery as one of many potential paths or steps that may be part of a person's transition (Denny 2004; Stryker 2017).

While for many people top surgery is a crucial part of gender transition, it involves substantial cost and several weeks of recovery time, and many barriers separate trans people from the medical procedures they need. Trans medical gatekeeping is common in many countries (Ashley 2019; Gill-Peterson 2018; Pearce 2018; Shuster 2021); in the U.S., insurance and cost barriers are prevalent, and in countries like the

U.K. where trans healthcare is covered by the state, barriers include long waitlists (Pearce 2018). In addition, many trans people lack family support (Nolan et al. 2020; Puckett et al. 2018) for surgery after-care.

Some of these gaps can be filled by community-based care work and mutual aid (Piepzna-Samarasinha 2018; Spade 2020). This type of care is what Hil Malatino (2020) calls “trans care,” which he defines as “what we owe each other” and a “commitment to showing up for all those folks engaged in the necessary and integral care work that supports trans lives, however proximal or distant, in the ways that we can” (Malatino 2019). Trans care describes all the ways that trans people care for each other, including caretaking around trans surgeries. But not all trans people have access to trans community and trans care in their physical locations. Online communities thus become an important mechanism for expanding trans care, increasing access to trans surgeries and reducing trans people’s reliance on traditional healthcare systems by providing vital health information and peer support. Trans care flourishes in online spaces, filling the gaps left by traditional systems that do not meet trans needs.

### **Online Health Communities for People with Marginalized Identities**

An increasing body of health research examines the specific health needs of people with marginalized identities. For example, Keyes et al. (2020) encouraged researchers to center “(gendered) marginalized health”—to focus on marginalized people’s health needs and make fewer assumptions about alignment between bodies, identities, and genders. In the spirit of this call, here we center trans men’s and nonbinary people’s medical and online community-based needs, thus making these marginalized groups more visible in social computing.

We focus on online spaces because they are especially helpful for trans people, who use them to find meaningful connection and support and share their experiences and personal narratives about their identity, both in recent years and historically (Buss et al. 2021; Dame-Griff 2023; Yeadon-Lee 2016). Participation in online health communities can help people cope with their condition, manage stress, and improve wellbeing (Rodgers and Chen 2005), and discussions of health conditions can help people translate medical concepts into practical knowledge (Pols 2014). In addition, health conditions can become part of one’s identity, and online health communities allow people to connect with others who share that identity (MacLeod et al. 2015). This is doubly true for people with health conditions who also have other marginalized identities, such as trans people; according to Pohjanen and Kortelainen (2016), trans people’s most important sources for information about gender transition were other trans people, who often provided reliable and detailed information about transition that was not available elsewhere.

There are other benefits to online community spaces for trans and LGBTQ+ people. The combination of anonymity and visibility that characterizes many social media sites allows users to explore and express their identity (Haimson et al. 2020; Haimson et al. 2021; Kitzie 2018; Kitzie 2019); online communities allow people to easily create and communicate multiple identities in ways which are often not possible in physical spaces (Haimson 2018; Haimson et al. 2021; Hanckel et al. 2019; R. Miller 2017). LGBTQ+ people can use online communities to connect with similar others, learn about gender and sexuality, and explore identities outside of their typical networks—an especially

important function for people who are not yet out (Byron et al. 2019; Cavalcante 2016; Dame 2016; Dym et al. 2019; Haimson 2018; Haimson et al. 2021; Hanckel et al. 2019; Oakley 2016; Simpson and Semaan 2021).<sup>1</sup>

Online communities are especially crucial for trans people, who face a severe lack of quality online health resources (Evans et al. 2017; Horvath et al. 2012). It is difficult to find accurate information about trans surgeries online (Karamitros et al. 2017), and even surgeons who perform gender affirming procedures sometimes provide inaccurate medical information about surgical procedures and complication rates (WPATH Open Letter). Similarly, photos of trans surgery outcomes can be difficult to access. (While post-surgery photos of trans patients are sometimes included in published research papers, these photos are often unethically published without patient consent; Marshall et al. 2018.) Online trans communities help with this problem also: many trans people share surgery outcomes on crowdsourced sites like Transbucket and social media like YouTube and Tumblr, as a way to visually track and document their transitions and to build community with others (Haimson et al. 2021; Prinsloo 2011; Raun 2015). Trans people use online spaces to connect with other trans people; to research gender and transition; to find resources; and to discuss and work through gender dysphoria (Chuanromanee and Metoyer 2021). However, these communities can be difficult to find, and as with any online resource, platform policies and misinformation sometimes hinder people from finding the health information they need (Augustaitis et al. 2021; Evans et al. 2017).

### **Storytelling, Narratives, and Decision-Making in Online Spaces**

Online trans communities offer a form of peer health navigation (Dowers, Kingsley, and White 2021) that positions trans people, rather than medical professionals, as experts on transness (Dame 2013). In these communities, people both adopt and critique common medical narratives to help them better understand themselves and their transitions (Psihopaidas 2017). Narratives are stories humans tell, individually and collectively, that transmit information and help them make sense of experiences. Storytelling can be a tool for community empowerment (Grimes et al. 2008), for it can be used to challenge dominant narratives (Gastaldo, Rivas-Quarneti, and Magalhães 2018) and provide community (Dym et al. 2019). Online storytelling has also been found to be useful for individuals, offering support (Høybye et al. 2005), solidarity, and activism (Gallagher et al. 2019).

Yeadon-Lee (2016) examined the role played by online narratives and storytelling in nonbinary identity formation and identity recognition across different age groups and stages of life. According to Yeadon-Lee, identity stories told online frequently presented certain elements: 1) authors used current labels to situate their identity within a shared framework of understanding, 2) authors expressed the inadequacy of these known terms and narratives to accurately describe their identity and experiences, 3) authors sought to reconstruct their own past histories in light of their current under-

1 However, online spaces are not trans and queer utopias. Trans people are sometimes restricted from participating in online spaces (Haimson and Hoffman 2016), and may face disproportionate harassment (Scheuerman, Branham, and Hamidi 2018). Further, some LGBTQ+ online spaces involve intra-community conflicts and harms (Walker and DeVito 2020).

standings of themselves, and 4) authors sought to relate their bodies to their identities (2016). These stories illustrate several of the ten features of narrative identified by Bruner (1991): they often *breach* or conform to *canonicity*, *accrue* through Internet archives, and either conform to or challenge *normativeness*.<sup>2</sup> We build from Yeadon-Lee's work to examine how transmasculine and nonbinary people in online health communities situate themselves and their identities alongside or in opposition to more commonly-told stories, and how this may affect decision-making.

In addition to enabling identity-related storytelling, online groups can also play an important role in health-related decision-making. Online groups may include not only patients themselves (Visser et al. 2016), but also healthcare providers and patient caregivers or supporters (Lau and Kwok 2009). Historically (and presently), healthcare providers have had undue decision-making power about trans people's medical care (shuster 2021), but online communities are changing this power dynamic, allowing patients to independently gather information about treatment options (Rupert 2016). We are interested in the role of online groups in decision-making surrounding gender confirmation surgery, given the paucity of information (relative to other, non-transition-related health information) and the unique social dynamics of such groups.

### **Platform Affordances for Health Communication and Storytelling**

Both health communication and storytelling can be discouraged or encouraged by platform affordances. To support health communication, affordances should support anonymity, pseudonymity, and privacy, because these enable people to comfortably share sensitive health information and information related to LGBTQ+ identity (Cho 2018; Hanckel et al. 2019; Kitzie 2019). Safety is also crucial; platform features that increase perceived safety in online spaces include privacy settings and enforcement of community standards to prevent harassment (Redmiles 2019). To support storytelling, affordances must also encourage sharing narratives and asking and answering questions (Hinson 2017). Health-related storytelling is supported by affordances related to flexibility, such as open-ended text boxes and tagging systems that use community-constructed terms—features that also enable identity exploration (Haimson, Dame-Griff et al. 2021; Oakley 2016). To promote LGBTQ+ storytelling and community building, platforms should have self- and audience-related affordances like high presentation flexibility and low identity persistence—features that are found on, for example, Tumblr (DeVito et al. 2017). Software for online health communities need not be technologically complex; the most important elements of supportive online spaces are affordances that enable strong community development (Maloney-Krichmar and Preece 2005).

We used both Facebook and Discord to hold online focus groups, offering insight on how each of these platforms' affordances may support health communication and storytelling. Discord is an excellent example of a platform that encourages strong community development: its social affordances promote self-expression and commu-

2 According to Bruner (1991), narratives have ten characteristic features: narrative diachronicity, particularity, intentional state entailment, hermeneutic composability, canonicity and breach, referentiality, genre, normativeness, context sensitivity and negotiability, and accrual. These features of narrative can be identified in stories people tell around gender transition and trans surgeries.

nity building, offering a sense of togetherness and community for people who are far apart (Vistisen and Jensen 2021). The platform enables text, audio, and video communication, and its affordances thus include synchronous and asynchronous communication, ephemeral and non-ephemeral content, custom user roles with visual markers, pseudonymity, and ability to host multiple communities (Bajpai et al. 2022). Discord's voice-based affordances can help to build community and enable storytelling, but they can also make moderation difficult (Jiang et al. 2019), and consequently, toxic environments and networked harassment are common on Discord (Heslep and Berge 2024). Yet prior work has not examined the extent to which Discord's affordances may uniquely support online health communication and storytelling; it is important to understand how platform affordances may hold important potential for trans people seeking health information, as we examine in this paper. In contrast, Facebook emphasizes affordances that tend to discourage both health communication and identity-based storytelling. First, it emphasizes identity persistence (DeVito et al. 2017), expecting people to represent their "real" selves on the platform -- an expectation that can make both trans identity presentation and sensitive self-disclosure difficult (Haimson and Hoffmann 2016). Second, Facebook is oriented toward "default publicness" rather than privacy, which can be dangerous for LGBTQ+ people (Cho 2017).

## **STUDY AND ANALYSIS**

In four asynchronous focus groups (two on Discord, two on Facebook), composed of  $N = 21$  total participants, we asked participants about top surgery and their decision-making process. We also asked how their online support communities (or lack thereof) affected their experiences. We chose to use asynchronous online focus groups (MacLeod et al. 2017; Prabhakar et al. 2017; Reisner et al. 2018) because the population of interest is both geographically distributed and stigmatized. This research was approved by the University of Notre Dame's Institutional Review Board, and each participant signed a consent form prior to participating in the study.

### **Participants**

We recruited  $N = 21$  participants who were either in the process of seeking top surgery or had had top surgery in the past. Participants' ages ranged from 18 to 31, with a mean age of 23.4 years, a median age of 24 years, and a standard deviation of 3.6 years. Twelve of the participants are currently in online support groups or have participated in them in the past; nine had no previous experience with online support groups. We recruited participants through several venues: social media posts on Twitter, Reddit, Facebook, and Tumblr; posts in online top surgery communities on Facebook, Discord, and Reddit; and our existing mailing lists of people interested in participating in research studies.

Participants reported a range of genders. Two participants were agender, eight participants identified solely as nonbinary, and three were both nonbinary and male. Five participants were male. One additional participant selected male and also wrote in "trans male," another wrote in "transmasculine," and one wrote that they were unsure whether they were "nonbinary or transmasculine nonbinary." When referring to a specific individual in this paper, we use their indicated pronouns.

Eight participants were white, four were Asian, three were Hispanic/Latino, one was Black, and five were mixed race. Nine of the participants indicated that they were disabled. Nineteen participants lived in the United States, one lived in Norway, and one lived in Canada at the time of the study.

Sixteen participants were “pre-op.” Of these, five reported that they wanted top surgery, but were unsure of how to get it. Three reported that they were trying to decide whether top surgery was something they wanted to pursue. The other eight participants were actively pursuing top surgery, taking steps such as saving money, scheduling appointments, or working with insurance companies to determine coverage. The other six participants had already had top surgery, from three months to five or more years before. Because of the potentially sensitive nature of the topics of discussion, our recruiting materials stated that the focus group moderator was in the transgender community and was familiar with top surgery. Participants were compensated with a \$30 payment via PayPal or Venmo.

Before submitting this article for publication, we gave participants the opportunity to read it and provide comments and corrections regarding their quotes and the overall narrative. One participant requested minor corrections of their quotes, which we adjusted before submission.

### **Focus Group Structure**

We conducted four online focus groups, two on Facebook and two on Discord, with each lasting three days. We chose Facebook because it has previously proven suitable for asynchronous online focus groups (MacLeod et al. 2017) and is beneficial for conducting research with hard-to-reach participants (Lijadi and Van Schalkwyk 2015). We included Discord, an online messaging platform focused on social connections and gaming, because it has recently become an important host for online trans communities, and the platform felt natural for many participants. While other platforms such as Tumblr were previously widely used by the trans community, the timeline format of the platform as well as the changes enacted in 2018 (Haimson et al. 2021) that alienated many trans users caused us to exclude it as an avenue for research.

Each day, in each community, the moderator posted two sets of prompts, one in the morning and one in the evening. This format is similar to that used by Reisner et al. (2018) and Augustaitis et al. (2021). In the Facebook groups, each set of prompts was posted as a separate post, and participants posted their replies in the comments. Participants could react to others’ comments and respond to them if they wished. Responses can be threaded, and participants can mention the poster of the comment using their name to clarify who the message is addressed to. In the Discord focus group, the structure was slightly different due to the platform’s setup. Each Discord group is called a “server”; usually there is one server owner and multiple moderators. Each server can have multiple channels (text or voice) for different topics or uses. Each member of the server can customize their name and avatar (and it can be different across different servers users belong to); members can send text, images, stickers, and files asynchronously to the server. Within each text channel, Discord allows replies and threading. This produces a free-flowing conversation format that can support multiple conversations occurring simultaneously.

In each focus group’s server, we created multiple text channels, each with its



own topic. The channels were:

#rules-info: used for posting the study information, informed consent documents, and rules for discussion.

#general: used for communication not directly related to the prompts or their responses.

#prompts: for the moderator to post the prompts. Posting privileges were restricted to only the moderator.

#prompts-responses: for participants to post their responses to the prompts, and to have conversations about topics related to the prompts.

We also had one voice channel open in case participants wanted to use it, but stated that this channel was completely optional.

The prompts on Discord and Facebook were the same. First, we asked participants to share their identities and backgrounds (if they were comfortable doing so) and where they were in terms of top surgery. We also asked them where they received support, their information-seeking habits, and the community dynamics of any online support groups they were in. Finally, we asked about their top surgery decision-making and what influenced that process.

## **Analysis**

We analyzed all data from each of the focus group transcripts (including images shared by participants and participants' use of platform-specific features) using open coding and axial coding (Strauss 1987). Axial coding helped us organize the data around larger themes and uncover the connections between themes. To keep participants' interactions and responses in context, we noted participants' use of emoji reactions during analysis (Reisner et al. 2018). Each member of the team separately conducted line-by-line open coding on the first focus group transcript. The team then met to discuss, refine, and consolidate codes, creating a collaboratively generated codebook. We then conducted axial coding (Strauss 1987). Finally, one of the authors used the collaboratively generated codebook to finish coding the rest of the focus group transcripts.

## **RESULTS**

Several themes emerged from our analysis, including participants' need for more comprehensive and inclusive representation of top surgery experiences, inequalities in accessing top surgery, and differing approaches to pursuing and obtaining top surgery.

We found that participants' experiences varied along each step of the top surgery decision-making process, which was deeply affected by internal and external factors such as health, socioeconomic status, access to care, social relationships, and identity discovery and presentation. Participants who had already had their surgery and who had previously participated in online top surgery support communities noted the online community's role in their surgery process and their experiences of gender dysphoria and gender euphoria.

Most, if not all, of the participants approached the decision about whether to

have top surgery as a momentous and significant one. Out of the 16 pre-op participants, eight were saving up for or were actively pursuing top surgery. Of the other eight, five wanted to have top surgery, but their present living, social, or financial situations prevented them from pursuing it; the other three were deciding whether or not they wanted to pursue top surgery. One of the three participants who was still deciding said they were torn because they feared regret post-surgery. Another participant decided to postpone making their decision until they have been on testosterone for at least a year.

The participants who had decided that they wanted top surgery reported various triggers for their decision. For instance, P6 started seriously considering top surgery less than a year ago, when they realized that their negative feelings from past years were not “sensory issues” but dysphoria. P18 said that they decided they wanted to have top surgery after they came to terms with their identity. For P16 and P6, factors affecting their decision and timing for top surgery included gender dysphoria and misgendering.

Other participants’ experiences were differently linked to social dynamics. For instance, P10 said that if it were not for societal expectations, he would not pursue top surgery. However, he felt uncomfortable sharing this information with other members of his focus group, and instead opted to directly message us with the following: “If there was a way for me to be shirtless as I am, or just un-bra’d un-binding as I am and still be respected as a male I don’t think I would have top surgery... There is a part of me that isn’t happy that I need surgery to have that kind of perception. To me, it’s almost a sacrifice I have to make.” P4 said almost the opposite: “I really do like the feeling of having a flat chest, as even if I don’t seem male, I do seem a lot less feminine, and that just feels so nice. (obligatory presentation =/ [does not equal] identity).”

### **Online Communities and Decision-Making**

The narratives (or lack thereof) and social situations that participants encountered helped them decide to pursue or delay pursuing top surgery. Many participants said that reading others’ stories in online support groups helped them decide to pursue top surgery: for example, P4 said, “I’ve looked at pictures of traditional top surgery, read and watched videos about people’s surgery experiences, and just read trans and nonbinary experiences in general and how they came to want top surgery.” Similarly, P4 reported that reading and watching others’ stories was helpful in deciding whether to pursue top surgery. For these participants, the stories found in online communities helped them decide to begin the process. Online groups provide participants with spaces to share these experiences, which can in turn help others with their decision-making processes.

Not everyone who decides to seek top surgery can immediately take concrete steps towards surgery. A number of participants said that it was impossible for them to get top surgery in the near future for many different reasons: progress in transitioning (P11), finances (P11, P1) and logistics (P1), and having other priorities for transition (P11, P18, P6), such as starting HRT. For many, the next step after deciding to pursue top surgery was waiting and gathering information and resources. The information participants gathered about top surgery came from many sources, including web searches, surgeons’ websites, and online communities on platforms such as Face-

book, Reddit, online blogs (P1), Youtube (P13, P14, P15), and TikTok (P15). While in this waiting phase, participants used online communities and resources more for support than for active decision-making, since there were not many concrete surgery-related decisions to make at this point. These communities helped participants cope with often uncontrollable life circumstances and barriers and provided them with a source of comfort and hope. Participants said that reading and viewing others' experiences with top surgery was helpful and served as a form of online self-care. Many participants reported feeling gender euphoria through seeing others' photos, which helped them through the period of waiting. P10 expressed: "I feel like most of the time when I look at top surgery results I'm kinda comforting myself, and I'd feel very comforted if I could see results that look like mine may look." Although P2 described feeling "a bit envious" when seeing others' results, they said, "It mostly gives me that gender euphoria feeling seeing fellow trans folks living their best lives and thinking about how someday that can be me!"

For most people who undergo top surgery, surgeon selection is a major decision—one that many participants made with the help of online communities. Many participants, including P4, looked for online recommendations before selecting a surgeon. We found that participants prioritized different criteria in making their surgeon selections; the criteria each person used to make decisions depended on their goals for the procedure. For example, P7's main criteria for surgeons were aesthetic—a preference that was informed by looking at others' results online. However, for P10, scars did not matter much, since "the biggest impact to my public life will be how clothes fit me on top, so the kind of scarring isn't something that I prioritize highly."

Not all participants found online communities equally useful for surgeon selection. In some countries or areas, there are stricter requirements for surgery or a limited number of surgeons. Most of the participants in our study described feeling at least somewhat limited in their surgeon selection. For instance, P20 lives in Canada, and is on a waitlist to speak with a surgeon. Due to local requirements, his top surgery would be fully covered if he were on hormones for at least one year. He said, "I have no say in that unless I pay extra money out of pocket. I just hope my surgeon and I get along well enough so I'm not afraid to say what I want." As P20's story shows, geographic restrictions and financial barriers sometimes combined to reduce participants' choice in surgeon selection. We see the same combination in P10, who is on an insurance plan that will fully cover top surgery, but only for select surgeons, only two of whom are in his state. These participants may find limited utility in online communities that share information primarily aimed at informing surgeon selection. In general, participants with more access and more choices tended to find online support groups more helpful.

Other participants may have criteria for surgeons that do not reflect most group members' criteria. Participants who inhabit bodies that are considered outside the norm (whether due to race, size, ability, or other factors) consistently reported a need for increased representation and support, and we found that their background and experiences can affect both their expectations for top surgery outcomes and their decision-making processes. For instance, some participants felt it was important to see a surgeon who has expertise or experience working with patients of their own race and/or body type. For P16, finances and experience with marginalized groups mattered the most. They remarked, "I think it would depend on whether there's any surgeons that

are in network for my insurance, but also I would highly prefer to see a surgeon who people of color had a good experience with.” While P19 went to a surgeon who did not have much experience with Black patients, he appreciated his surgeon’s honesty about this: “I remember at my surgery consult she was very upfront with me about having not done top surgery on a person with my skin tone so she didn’t know how the scars would turn out. This made me trust her way more in the process.”

Many participants noted a need for more diverse representation in size, shape, race, and ability in online groups (echoing findings from Andalibi et al. 2022), surgery narratives, and pictures of results. As P16 put it: “[I] would love some resource that is more QTPOC centered or QTPOC only and to readily be able to see how top surgery looks on a variety of bodies (skin tones, body shape, and fat level, etc).” Similarly, P15 remarked: “I wish it was easier to see results. I also wish there were more resources available for people who aren’t thin/have smaller chests.” P19 said, “[I was] on [a popular Facebook top surgery group] specifically wanting to talk to black folks who had had top surgery and there was virtually no one...We put the trans guys who have top surgery and have minimal scars or scarring, didn’t have to do nipple grafts, and were buff before surgery and buff after surgery on a pedestal as what everyone wants to look like and what everyone will look like. I think it’s cool to see results but I wish we focused on results from all body types and races and not just trans guys who win the genetic passing lottery.” For P19, because most resources showed “ideal” results, he was not able to find and connect with other black trans people (P19 here echoes prior work that described lack of online examples of trans surgery results for people of color; Haimson et al. 2021). However, some participants were able to find support from others with similar backgrounds in larger, more mainstream groups; P21 was able to find support and representation in a large general top surgery group when other Asian people posted their results, and P11 used others’ experiences online to determine what decisions he needed to make regarding top surgery: “I try to find others who have similar body types to me and similar experiences, so I know which decisions would work best for me.” Although he said that he may change these decisions after talking with a surgeon, others’ stories helped provide him with a jumping-off point to make his preliminary decisions.

We also saw some evidence that participants’ disabilities affected their decision-making and expectations. P11, who is disabled, expressed: “I’d like more experiences from disabled trans men such as myself. Being disabled can mean top surgery/gender confirmation may be less priority than working on other health issues, and some disabled people may not even be able to have gender confirmation surgeries at all. When looking up information about disabled trans peoples’ experiences with transition, it can be difficult to find any information.” P11’s difficulties in finding other disabled trans people’s stories applied not only to top surgery but to gender transition in general. P20 recognized the limitations of top surgery as it relates to his disability and adjusted his expectations, saying, “My severe scoliosis would make it impossible to achieve a natural looking result.”

Other participants, such as P15, wanted more support and representation of people of size: “I am currently a size 16 and I have rarely seen resources/topics for people my size and up.” This is a concern often grouped together with a more general desire for increased representation of marginalized bodies, as P15 and P16 expressed

above. P7's surgical decision-making also included deciding whether to have liposuction as an additional procedure during their top surgery; participants' perception of their bodies can affect their satisfaction with their surgical decisions and results.

Just as participants wished for better representation of race, body type, and ethnicity in online top surgery communities, they also reported a need for more resources for people with non-traditional experiences of gender. Many participants did not strictly consider themselves transmasculine, and they described feeling that there was a lack of online spaces where people would accept them. For instance, P6 said: "I think a lot of top surgery discussions tend to be geared exclusively toward binary trans men, which can make anyone else interested in the possibility of getting it feel kind of lost, or forgotten." Such groups can feel alienating for somebody who does not identify as a binary trans man. Many participants in this category gravitated toward non-traditional top surgery procedures, pursuing a reduction rather than a complete removal. P5 learned that breast reduction was an option through seeing others' experiences on TikTok: "I didn't realize other people were like this until like a month ago when a gender surgeon on tiktok posted something about how 'many genderqueer people go for reductions that make it easier for them to bind!' and I got very excited that this was AThing, and it solidified it in my mind as something that was possible to achieve."

Although, as these participants' stories show us, trans resources online are not thorough, all-encompassing, and perfectly suited to every type of body and situation, there is value for most in spending time in online trans communities as they make their decisions about top surgery. Online platforms can empower people to feel more knowledgeable and in control over their decision-making processes, in part because these communities provide space for people who have finished their surgeries to share their stories. These stories were valuable whether or not participants interacted directly with other members of the online communities. Many participants said that seeing others' results and learning about options regarding different surgery procedures helped them feel more prepared to make their own decisions, even if they did not necessarily interact directly with other group members. P4 pointed out, "[Lurking in online groups] ha[s] been helpful in consolidating a variety of information, from details about finding doctors, talking about how some places have prerequisites to getting top surgery, the recovery process, as well as different people's experiences throughout that process. [This] has been helpful in figuring out insecurities regarding it, or doubts I've had."

Many participants described prioritizing both physical and mental health when navigating online communities and making decisions regarding top surgery, including P10: "I'm just happy to be able to get the surgery for free and I don't want to undermine my own happiness being picky or extra selective." This prioritization of self-care also extended to making decisions about continued participation in surgery- or trans-related groups. For example, P19 left a top surgery-related group because "It skewed my perception on what my results should look like. I think it ended up saving my mental health and self esteem by leaving the group because my results were so drastically different than the results being posted by other people at the time." Similarly, P17 noted that "When I joined groups before knowing if I could transition, I had a lot of jealousy and needed to pause participation for a while for my own mental health." P19 also noted that group dynamics were harmful at times: "Definitely jealousy was super

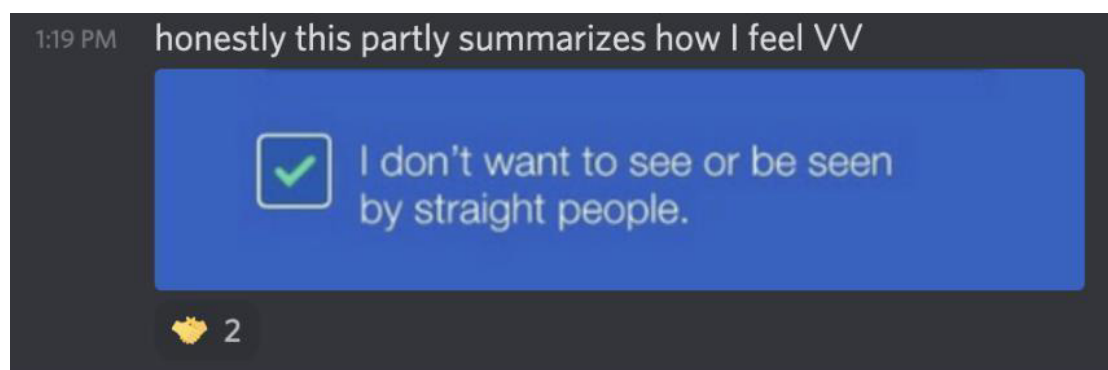
common. I also think it was common to bad mouth results especially when people had really dark scars or nipples/areolas that weren't perfect circles. It was definitely pretty toxic at times." While many participants found online groups helpful and supportive, others chose to remove themselves from such groups because of the harm that comes from comparison and jealousy.

### **Role of Storytelling**

Many participants said that their decision-making processes benefited from others' storytelling in online trans communities—posting before and after pictures or writing about their experiences. For example, P4 mentioned that reading about others' experiences helped them consolidate information and feel more confident and less insecure in pursuing top surgery and making decisions. Several participants said that these stories helped them decide what questions to ask their surgeons, set expectations for their own processes, and realistically understand potential results. P4 commented, "Stories like that would be very helpful for people figuring themselves out."

In the focus groups, we learned that participants found several different types of storytelling – including text/photo-based and vlog-based storytelling –helpful for their decision-making. Stories that include both text and photos (usually before and after pictures of the person) may be fairly comprehensive, documenting the entire process before and after surgery, or they may be smaller in scope, documenting individual segments of the person's journey, such as the recovery process post-surgery. Vlog-style videos invite the viewer to participate in the storyteller's experience, as the teller and the viewer share the "sense of the passing of time" (which can affect expectations of transition timelines; Horak 2014). Videos documenting top surgery-related experiences may allow viewers to feel more personally connected to the storyteller (Raun 2015) (which can be a form of parasocial relationship; Horton and Wahl 1956), creating a more immersive experience than text- and photo-based stories.

Most of the five post-op participants mentioned that after surgery, they stayed in the top surgery groups that they were active in before surgery. P17 remained in online groups to impart his knowledge and experiences to others. P8, who had surgery



**Figure 1. A screenshot of a post shared by P2, who used this image to convey their feelings surrounding being perceived by others. The handshake emoji reactions are from two other participants, which shows signs of supportiveness and camaraderie.**

less than six months before he participated in this study, was still using online support groups to get reassurance and answers to questions about healing and scar care routines because it felt less overwhelming, intimidating, and anxiety-inducing to ask group members than to contact his surgeon directly. P14 had a similar experience with a transmasculine Asian American online group chat.

Many participants found the research spaces themselves to be supportive online community environments. Participants were engaged with the focus group discussions, with 20 of 21 participants responding to a majority of prompts posted, and 18 responding to all prompts. Participants interacted not only with the prompts we posted, but also with each other (e.g., by commenting on and reacting to each other's posts). In one Discord group, P6 expressed that he had never considered a reduction as a possibility until he talked with P4: "I hadn't even thought of a reduction mastoplasty; I'm already so glad I joined this group because that had never occurred to me but might be something I'd be interested in because of my concerns about sensation. Hmm, I'm definitely gonna check that out."

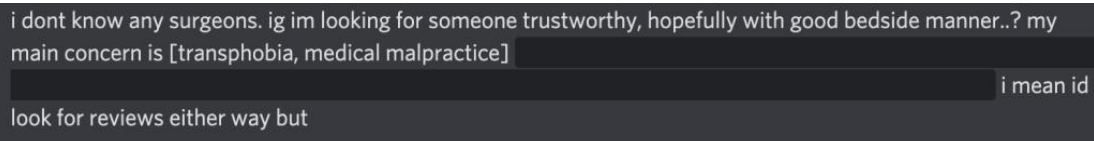
Even within the structure of the focus group, P6 and other participants expressed positive emotions about the benefits they received from participating in the focus groups. P6's participation in the focus group also influenced his decision-making process. P6 remarked, "After the conversation I had with P4, I'm definitely going to look into reduction as an alternate possibility." From his conversations with P5, P6 will think about changing the type of procedure he pursues, which adds another factor into his decision-making process.

### **Discord and Facebook Affordances That Shaped Research Spaces into Supportive Online Community Environments**

Affordances on the two focus group platforms shaped participants' communication with each other throughout the study, primarily in ways that enabled lightweight expressions of support. Discord contains user-applied content (or "spoiler") warnings, while Facebook does not. We saw that the Discord groups intentionally utilized trigger or content warnings and hid potentially triggering content under spoiler tags (which hide the content unless the reader clicks on it) without prompting from us or the other participants. Content warnings help people in online communities care for each other by giving others the choice to not read or view content that may be difficult for them at that time; for instance, a person facing insurmountable barriers to surgery may find it difficult to read about others' successful surgery journeys (Haimson et al. 2020).

Furthermore, the anonymous nature of Discord and the network separation offered by the platform through using separate servers (and usernames and avatars) could have allowed participants to feel more comfortable sharing different, more personal information compared with Facebook. Although we told participants that they could create or use a different account that is not their personal account to participate in the Facebook focus groups, most participants used a profile that could be linked to their identity. Facebook by nature uses participants' full names (and often images of themselves), which were publicly available to other focus group participants.

We see the potential impact of these affordances in how the different focus group members participated in the study. Across all of the focus groups on Discord and Facebook, participants sent 793 messages consisting of 23,960 words. The average length

A screenshot of a social media post. The text is partially obscured by a black bar. The visible text reads: "i dont know any surgeons. ig im looking for someone trustworthy, hopefully with good bedside manner..? my main concern is [transphobia, medical malpractice]". Below this, there is a black bar with the text "i mean id" on the right side. At the bottom, it says "look for reviews either way but".

i dont know any surgeons. ig im looking for someone trustworthy, hopefully with good bedside manner..? my main concern is [transphobia, medical malpractice]

i mean id

look for reviews either way but

**Figure 2. A screenshot of a post by P5, which includes a content warning and use of spoiler tags to hide the sensitive content. Focus group participants who choose to read it can click on the black bar to reveal the text.**

of messages varied for each group, with the highest being 38 words (a Facebook group) and the lowest being 26 words (a Discord group). Both Discord and Facebook provide ways for participants to support each other through reactions and replies, and these “react” or “like” features were used by participants in all focus groups. One Discord group had the highest number of reactions: 45 in total. The lowest was the other Discord group, with four in total. The Facebook groups had 24 and 19 likes, respectively.

## DISCUSSION

Most participants’ experiences were likely affected by the current anti-trans political climate, especially in the U.S., where most participants lived. This hostile climate made in-person spaces for gathering knowledge and support increasingly precarious, likely influencing people’s use of private online spaces to discuss top surgery decisions. Thus, it is important to explore the role these online communities play as spaces for holding and sharing knowledge and supporting trans care. In the following sections, we draw from and extend previous literature to discuss the relationship between storytelling, sensemaking, and decision-making and examine how online communities support trans care and collective self-care. We offer suggestions for online platforms that wish to encourage trans storytelling and community and provide suggestions for researchers using asynchronous focus groups, pointing out the usefulness of Discord as a research tool.

### Implications for Online Communities

#### *Storytelling affects sensemaking and decision-making*

Previous research about storytelling found that it is a valuable tool for centering marginalized experiences. We extend this research by focusing specifically on stories told about gender affirming surgery and the ways in which group members receive and process such stories, examining how several of Bruner’s narrative features manifest and are challenged in these narratives. The narrative features we focus on are canonicity, breach (often through deconstruction), genres, normativeness, and accrual (Bruner 1991).

In the case of top surgery, there is a canonicity about common cultural stories about pre-transition life, in which trans people were “trapped in the wrong body” and suffer from devastating levels of dysphoria. This canonical story was breached several times during the study; participants acknowledged that this canon was not true of their own stories, challenging the cultural story surrounding top surgery. We identified genre features, noting that different narratives emerged around top surgery for



trans men, nonbinary people, and people who are questioning their gender. Normativeness was explicitly acknowledged by several participants who described their experience as differing from the canonical stories about pre-transition life, top surgery, and gender. Accrual, defined as the combination of stories to create a larger shared narrative, is seen both in existing online trans groups and also in the focus groups. For instance, participants who spoke about seeking a reduction versus total removal contributed their individual stories to the group's overall narrative.

These stories and their reception in online top surgery communities help us understand collective sensemaking and show us how experiences that line up with or challenge cultural expectations are treated in these groups. The ways participants used stories in making decisions surrounding top surgery are similar to the use of stories in other decision-making processes, where stories function as information and evidence to make decisions (Metoyer et al. 2020). In this way, the stories told in online top surgery groups facilitated sensemaking among participants. More work is needed, but certain platform affordances could be implemented to help trans people aggregate information and structure their transition-related decision-making processes. To challenge the normativeness and canonicity that exclude certain trans experiences (and to ensure that these non-normative experiences accrue to larger trans stories), platforms should work to include the voices of those who inhabit more marginalized bodies, encouraging them to tell their stories and amplifying their narratives. Platforms must also provide a safe space where community members feel that they can share without fear of judgment. For example, platforms might consider giving incentives to attract content moderators and community leaders who are part of those marginalized communities, as moderation is traditionally a volunteer position. Scheuerman, Branham, and Hamidi's (2018) suggestions to focus on the more "normative, incidental, subtle, and mundane violations" and not simply more obvious and egregious issues should be considered to prevent common intra-community harms. Other platform affordances can encourage safe sharing and connection. Currently, both Discord and Facebook allow direct message functionality, however, this feature is difficult to find for people new to online communities or specific platforms. On Facebook, direct messages from non-Facebook friends go to a separate inbox that is difficult to find, and they often remain unread. It is also difficult to know whether someone is open to direct messages or not; the use of icons or other signifiers can indicate that someone is willing to engage in more personal conversation via private message. Discord offers a useful alternative to direct messaging: it allows moderators to designate certain text channels as private—available only to server members who hold certain role permissions in the server. These private channels can be used to share more sensitive or private stories with a smaller, more intimate group.

### *Online communities can facilitate trans care and collective self-care*

Collective self-care—a form of "therapeutic collectivity"—challenges the notions of sole individual responsibility for health, recognizing that trauma is often experienced at a community level rather than individually (Chudakova 2017; Ortega-Williams 2021). Because suffering came from a social context, its resolution must be in the same context (Ortega-Williams 2021). Collective self-care thus can be a means of coping with systemic violence. Collective self-care is manifested by showing up for oneself and for

one's community, supporting each other emotionally and sharing resources and information for survival (Ortega-Williams 2021). This notion of collective self-care is similar to Malatino's trans care (2020), but trans care centers care for others, while collective self-care emphasizes the personal therapeutic benefits of helping others in a community with shared oppressions.

Participating in top-surgery related trans online communities may be a form of self-care, for many participants described that such participation in online communities had helped to improve their mental health and/or gender dysphoria. For instance, P10, who is pre-op, said that viewing top surgery results was a means of comforting himself. Seeing others' results helped him envision what his own might look like, in a way giving him hope for the future. Similarly, P12 stated that seeing others' results gave him gender euphoria and helped him think about how that is in his future. Online groups thus seem to be particularly helpful during gatekeeping or waiting periods during the top surgery-seeking process.

In addition to collective and individual self-care, online trans support communities also provide trans care, which goes beyond the forms of care found in many other communities. This is because trans care is based on a feeling of solidarity and shared experience in the face of marginalization, stigmatization, and limited access to healthcare and traditional mechanisms of support such as family. In what follows, we describe how online communities can provide and facilitate trans care.

First, we saw trans care in the focus groups where participants offered each other support (such as P6 commiserating with P2 about chronic pain), even when they did not previously know each other or live in the same area. Participants also validated each other's non-normative experiences with gender and labels, such as P2, P4, and P5's conversation about the fact that none of them preferred to describe themselves using the word transmasculine. While these interactions were fairly brief, they illustrate how group members supported other trans members through validation and emotional labor. Even group members who did not share many things in common supported each other around conflicts in home life and resource sharing, proved to be means of what Malatino calls "a difficult practice of love across difference in the name of coalition and survival," which does not require sameness across all identity facets (Malatino 2019).

While the support participants received and provided not necessarily life-changing, and it did not change the institutional barriers and systemic challenges trans people face, these support acts in online communities were "guided by a commitment to trans love, small acts that make life more livable in and through difficult circumstances" (Malatino 2019). Online platforms such as Facebook and Discord facilitate such support, even when there is vast geographical distance between group members. Small acts of care or solidarity in online communities (like those seen in our groups via emoji reactions) are a form of trans care praxis that is "simultaneously practical...and ephemerally affirmative" (Malatino 2020).

In addition to trans care, many online communities also facilitate collective self-care. According to Schönbauer (2020), collective self-care is present when a space provides some respite for its participants and allows them to express parts of themselves that cannot be shown to others. In a collective self-care space, participants can shift from being a minority to being a majority, and the space helps members cope

with feelings such as loneliness and isolation (Schönbauer 2020). We saw this type of collective self-care in our focus groups. For participants in our study, using content warnings was an unspoken agreement and a way of caring for one another in this online space where members were sharing sensitive and personal information. While supporting online spaces may not materially change participants' problems (Schönbauer 2020), they can help people cope with the stresses of life, transphobia, and lack of community. Spaces for collective self-care can also involve "collective engagement in which accomplishments are shared" (Schönbauer 2020); we saw these forms of collective trans self-care as participants shared stories of secondhand gender euphoria.

### **Trans Discord Communities as Trans Technologies**

Not all social media platforms are viable for trans communities, often because of a lack of a significant trans user base, restrictive content policies, features that are not conducive to privacy, and lack of protection against abuse and harassment. Some platforms have features that make them not only viable but actively helpful for trans communities. Discord is such a platform. In Discord servers that host insular trans online communities, trans moderators can set policies and norms that make the platform very trans-friendly: they can allow people to share trans surgery content, regardless of how "explicit" it is; they can enable privacy protections; and they can protect against transphobic abuse.

While more research is needed to confirm this, and while this alone does not make Discord better than other available technologies, these affordances indicate that Discord online trans communities may be a "trans technology," as defined by Haimson et al. (2021): a technology enabling identity "realness, change, and network separation, along with the queer aspects of multiplicity, fluidity, and ambiguity, necessary for gender transition." Discord has many features that support trans experiences. First, since many Discord servers are invitation-only, they can be designated as spaces for marginalized communities to share their experiences, because the messages posted by server members are visible only to those who are part of the same community. This type of Discord server has the quality of "openness": it is a "safe and comfortable place where people could reveal sensitive information, be understood, and tell secrets" (Haimson et al. 2021). In our focus groups, the Discord groups in particular allowed participants to openly question their identities and reevaluate decisions they were making about top surgery procedures. Discord also facilitated what Haimson et al. (2021) called "network separation." Compared to platforms such as Facebook, which require that participants use their real names, Discord allows members to be anonymous, separating the content they share there from their real-life networks where they are known. The anonymity of Discord thus allowed our participants to push back against normative, prescribed transition narratives (Billingsley 2015). Discord enabled participants to speak to and interact with similar others about their lived experiences related to trans identity—one of the central features of a trans technology (Haimson et al. 2021). But we cannot say that Discord itself is a trans technology, only that particular servers that meet particular conditions may be; the same Discord features that enable trans online communities to thrive also enable hate and transphobic content in other servers (Heslep and Berge 2024).

Of course, many online spaces where trans people gather may meet some of the

criteria to be considered a trans technology. However, we argue that for an online community to entirely qualify as a trans technology, it must uniquely enable trans care and support trans narratives (which Discord can at the server level, but not at the platform level). While more research is needed to fully understand the differences between how trans people practice trans care on Discord and on other platforms, in our study, we witnessed trans care much more explicitly in the Discord groups than the Facebook groups.

### **Discord as a Tool to Facilitate Online Asynchronous Focus Groups**

Online spaces are especially important when it comes to facilitating focus groups. Here, we extend prior work on Discord's affordances (Bajpai et al. 2022; Vistisen and Jensen 2021) to show that in addition to being an important platform for community building, Discord is also specifically useful for health communication and storytelling and a useful tool for researchers. The first affordance that makes Discord useful for research is its asynchronous focus group format, which allows more time for participants to think through their answers and digest others' responses than in synchronous in-person focus groups. It is also pragmatically useful for research into topics where there is not a large local population of suitable participants—for example, areas where there is a limited trans population or representation, or where it is dangerous to be openly trans. Online groups can make focus groups possible when in-person focus groups are difficult or impossible to organize.

While using Discord to run focus groups is a fairly new approach, we found that the Discord servers we used in our research enabled participants to build connections and support each other in many ways that we did not see in the Facebook groups, as evidence from the greater number of interactions and reactions in the Discord groups. We found that Discord facilitates a more free-flowing, less-structured format for discussions than Facebook, and this allowed participants to take a more natural, conversational approach. Participants could jump in and respond to more than one person at once and react to others' messages with emoji to show support or reactions. While these activities are also possible on Facebook, the features and "culture" of Discord may have facilitated this more conversational style. Discord participants sent a higher number of messages with a shorter average message length than Facebook participants did. Discord's multiple text channels also offered benefits for focus group research, as they segmented conversations based on topic and tone and supported multiple conversations happening at the same time. This produced more in-depth conversations in the Discord groups than in the Facebook groups.

Discord also helped us as researchers build a better rapport with participants than Facebook. This may be due to the increased anonymity that the Discord server affords. Facebook requires participants to share their first and last names, and their participation is attached to their main Facebook account, which can cause self-presentation problems for trans people (Haimson and Hoffman 2016); in contrast, Discord users generally have anonymous or pseudonymous handles that cannot be used to identify the person associated with the account. This is particularly important for users who need to obscure their identity due to oppression or unsupportive environments.

We also observed that the Discord group members took others' mental health

into account by using content warnings and spoiler tags (where Facebook does not have these capabilities). While emoji reactions are possible in both Discord and Facebook, it is likely that Discord's more anonymous, casual nature encouraged the use of these features. Platforms that encourage content warnings are useful for focus groups with sensitive topics, as this allows for a safer environment for participants. One caveat is that just because a focus group is on Discord, it does not necessarily mean that it will have much interaction; it depends upon the focus group composition and on social modeling (for example, of emoji reaction usage). One of our Discord groups had only four emoji reactions during the entire duration of the focus group. Discord can be a powerful tool, but it does not guarantee a high level of interaction; that depends on the participants' existing online habits and on moderator modeling of particular interaction behaviors.

### **Limitations**

We only focused on transmasculine and nonbinary top surgery, so our findings may not be applicable to all types of gender confirming surgery. Because the majority of the participants had not had top surgery at the time of the focus groups, we saw more discussion on pre-surgery decisions than post-surgery decisions, and we were not able to ascertain how much people would continue to participate in support groups after top surgery. We also did not examine the amount of participation in such communities, the number of people who did not choose to participate in such groups, or other topics, such as the role of content moderation in these groups. Furthermore, due to participants' relatively young age range, we were not able to learn about information-seeking habits and narratives of those who obtain top surgery later in life; these habits and narratives may be different for those over 30, as well as those who live in other geographical regions. Finally, while the features for Discord and Facebook are described at the time of data collection and writing, they are constantly changing and may be different in the future. Further, we recognize that all platform affordances should be considered in the context of the platforms' and its owners' politics, which often substantially impact and constrain how marginalized communities use the site.

### **CONCLUSIONS AND FUTURE WORK**

By analyzing data from four online asynchronous focus groups of 21 individuals who sought top surgery or have recovered from top surgery, we have improved our understanding of the forms and roles of storytelling in trans health online communities and have described how online surgery support spaces can facilitate both trans care and collective self-care. From our experience conducting this study, we provide research recommendations for conducting focus groups that are built around shared intersecting identities, and identify the benefits of using Discord, an emerging online platform, in facilitating online asynchronous focus groups. While we were able to provide insights about the dynamics of top surgery support communities, future work should focus on other forms of gender confirmation surgery to determine whether our results extend to other types of trans surgeries and other groups of participants. We focused on decision-making and storytelling in trans online health communities, but we also observed that participants also used these communities as a sensemaking tool; future

work should investigate the role of online communities in individual and collective sensemaking in gender transition and health management. Additional work can also investigate the relationship between social media affordances and how support groups function, and on the use of Discord as a focus group tool for research.

## REFERENCES

- Ashley, Florence. 2019. "Gatekeeping Hormone Replacement Therapy for Transgender Patients is Dehumanising." *Journal of Medical Ethics* 45 (7): 480–82.
- Andalibi, Nazanin, Ashley Lacombe-Duncan, Lee Roosevelt, Kylie Wojciechowski, and Cameron Giniel. 2022. "LGBTQ Persons' Use of Online Spaces to Navigate Conception, Pregnancy, and Pregnancy Loss: An Intersectional Approach." *ACM Transactions on Computer-Human Interaction (TOCHI)* 29 (1): 1–46.
- Augustaitis, Laima, Leland A. Merrill, Kristi E. Gamarel, and Oliver L. Haimson. 2021. "Online Transgender Health Information Seeking: Facilitators, Barriers, and Future Directions." In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, 1–14.
- Bajpai, Tanvi, Drshika Asher, Anwesa Goswami, and Eshwar Chandrasekharan. 2022. "Harmonizing the Cacophony with MIC: An Affordance-Aware Framework for Platform Moderation." *Proceedings of the ACM on Human-Computer Interaction* 6 (CSCW2): 1–22.
- Billingsley, Amy. 2015. "Technology and Narratives of Continuity in Transgender Experiences." *Feminist Philosophy Quarterly* 1 (1).
- Bluebond-Langner, Rachel, Jens U. Berli, Jennifer Sabino, Karan Chopra, Devinder Singh, and Beverly Fischer. 2017. "Top Surgery in Transgender Men: How Far Can You Push the Envelope?" *Plastic and Reconstructive Surgery* 139 (4): 873e–882e.
- Bruner, Jerome. 1991. "The Narrative Construction of Reality." *Critical Inquiry* 18 (1): 1–21.
- Buss, Justin, Hayden Le, and Oliver L. Haimson. 2021. "Transgender Identity Management Across Social Media Platforms." *Media, Culture & Society* 44 (1): 22–38.
- Byron, Paul, Brady J. Robards, Benjamin Hanckel, Son Vivienne, and Brendan Churchill. 2019. "Hey, I'm Having These Experiences': Tumblr Use and Young People's Queer (Dis)connections." *International Journal of Communication* 13 2239–59.
- Cannon, Yuliya, Stacy Speedlin, Joe Avera, Derek Robertson, Mercedes Ingram, and Ashely Prado. 2017. "Transition, Connection, Disconnection, and Social Media: Examining the Digital Lived Experiences of Transgender Individuals." *Journal of LGBT Issues in Counseling* 11 (2): 68–87.
- Cavalcante, Andre. 2016. "'I Did It All Online': Transgender Identity and the Management of Everyday Life." *Critical Studies in Media Communication* 33 (1): 109–22.
- Cipolletta, Sabrina, Riccardo Votadoro, and Elena Faccio. 2017. "Online Support for Transgender People: An Analysis of Forums and Social Networks." *Health & Social Care in the Community* 25 (5): 1542–51.
- Cho, Alexander. 2018. "Default Publicness: Queer Youth of Color, Social Media, and Being Outed by the Machine." *New Media & Society* 20 (9): 3183–200.
- Chuanromanee, Tee, and Ronald Metoyer. 2021. "Transgender People's Technology

- Needs to Support Health and Transition.” In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, 1–13.
- Chudakova, Tatiana. 2017. “Caring for Strangers: Aging, Traditional Medicine, and Collective Self-Care in Post-Socialist Russia.” *Medical Anthropology Quarterly* 31 (1): 78–96.
- Craig, Shelley L., Andrew D. Eaton, Lauren B. McInroy, Vivian W. Y. Leung, and Sreedevi Krishnan. 2021. “Can Social Media Participation Enhance LGBTQ+ Youth Well-Being? Development of the Social Media Benefits Scale.” *Social Media + Society* 7 (1).
- Dame, Avery. 2013. “‘I’m Your Hero? Like Me?’: The Role of ‘Expert’ in the Trans Male Vlog.” *Journal of Language and Sexuality* 2 (1): 40–69. <https://doi.org/10.1075/jls.2.1.02dam>.
- Dame, Avery. 2016. “Making a Name for Yourself: Tagging as Transgender Ontological Practice on Tumblr.” *Critical Studies in Media Communication* 33 (1): 23–37.
- Dame-Griff, Avery. 2023. *The Two Revolutions: A History of the Transgender Internet*. New York: New York Press.
- Denny, Dallas. 2004. “Changing Models of Transsexualism.” *Journal of Gay & Lesbian Psychotherapy* 8 (1–2): 25–40.
- DeVito, Michael A., Jeremy Birnholtz, and Jeffery T. Hancock. 2017. “Platforms, People, and Perception: Using Affordances to Understand Self-Presentation on Social Media.” In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing*, 740–54.
- Dowers, Eden, Jonathan Kingsley, and Carolynne White. 2021. “Virtually Trans: An Australian Facebook Group Supporting Gender Diverse Adults’ Health and Wellbeing.” *Health Promotion International* 36 (1): 196–205.
- Dym, Brianna, Jed R. Brubaker, Casey Fiesler, and Bryan Semaan. 2019. “Coming Out Okay’: Community Narratives for LGBTQ Identity Recovery Work.” *Proceedings of the ACM on Human-Computer Interaction* 3 (CSCW): 1–28.
- Evans, Yolanda N., Samantha J. Gridley, Julia Crouch, Alicia Wang, Megan A. Moreno, Kym Ahrens, and David J. Breland. 2017. “Understanding Online Resource Use by Transgender Youth and Caregivers: A Qualitative Study.” *Transgender Health* 2 (1): 129–39.
- Gallagher, Ryan J., Elizabeth Stowell, Andrea G. Parker, and Brooke Foucault Welles. 2019. “Reclaiming Stigmatized Narratives: The Networked Disclosure Landscape of #MeToo.” *Proceedings of the ACM on Human-Computer Interaction* 3 (CSCW): 1–30.
- Gastaldo, Denise, Natalia Rivas-Quarneti, and Lilian Magalhães. 2018. “Body-Map Storytelling as a Health Research Methodology: Blurred Lines Creating Clear Pictures.” In *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research* 19 (2): 1–26.
- Gill-Peterson, Jules. 2018. *Histories of the Transgender Child*. Minneapolis: University of Minnesota Press.
- Grimes, Andrea, Martin Bednar, Jay David Bolter, and Rebecca E. Grinter. 2008. “EatWell: Sharing Nutrition-Related Memories in a Low-Income Community.” In *Proceedings of CSCW*, 87–96.
- Høybye, Mette Terp, Christoffer Johansen, and Tine Tjørnhøj-Thomsen. 2005. “Online

- Interaction: Effects of Storytelling in an Internet Breast Cancer Support Group.” *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer* 14 (3): 211–20.
- Haimson, Oliver L., and Anna Lauren Hoffmann. 2016. “Constructing and Enforcing ‘Authentic’ Identity Online: Facebook, Real Names, and Non-Normative Identities.” *First Monday* 21 (6).
- Haimson, Oliver. 2018. “Social Media as Social Transition Machinery.” *Proceedings of the ACM on Human-Computer Interaction* 2 (CSCW): 1–21.
- Haimson, Oliver L., Justin Buss, Zu Weinger, Denny L. Starks, Dykee Gorrell, and Briar Sweetbriar Baron. 2020. “Trans Time: Safety, Privacy, and Content Warnings on a Transgender-Specific Social Media Site.” *Proceedings of the ACM on Human-Computer Interaction* 4 (CSCW2): 1–27.
- Haimson, Oliver L., Avery Dame-Griff, Elias Capello, and Zahari Richter. 2021. “Tumblr Was a Trans Technology: The Meaning, Importance, History, and Future of Trans Technologies.” *Feminist Media Studies* 21 (3): 345–61.
- Hanckel, Benjamin, Son Vivienne, Paul Byron, Brady Robards, and Brendan Churchill. 2019. “‘That’s Not Necessarily for Them’: LGBTIQ+ Young People, Social Media Platform Affordances and Identity Curation.” *Media, Culture & Society* 41 (8): 1261–78.
- Harner, Vern. 2021. “Trans Intracommunity Support & Knowledge Sharing in the United States & Canada: A Scoping Literature Review.” *Health & Social Care in the Community* 29 (6): 1715–28.
- Hawkins, Blake, and Jen Jack Giesecking. 2017. “Seeking Ways to Our Transgender Bodies, by Ourselves: Rationalizing Transgender-Specific Health Information Behaviors.” *Proceedings of the ASIST* 54 (1): 702–4.
- Hawkins, Blake W., and Oliver Haimson. 2018. “Building an Online Community of Care: Tumblr Use by Transgender Individuals.” In *Proceedings of Gender & IT*, 75–77.
- Heslep, Daniel G., and P. S. Berge. 2024. “Mapping Discord’s Darkside: Distributed Hate Networks on Disboard.” *New Media & Society* 26 (1): 534–555.
- Heyes, Cressida J., and J. R. Latham. 2018. “Trans Surgeries and Cosmetic Surgeries: The Politics of Analogy.” *TSQ: Transgender Studies Quarterly* 5 (2): 174–89.
- Hinson, Katrina L. 2017. “Framing Illness Through Facebook-Enabled Online Support Groups.” *Communication Design Quarterly Review* 4 (2b): 22–31.
- Horak, Laura. 2014. “Trans on YouTube: Intimacy, Visibility, Temporality.” *TSQ: Transgender Studies Quarterly* 1 (4): 572–85.
- Horton, Donald, and R. Richard Wohl. 1956. “Mass Communication and Para-Social Interaction: Observations on Intimacy at a Distance.” *Psychiatry* 19 (3): 215–29.
- Horvath, Keith J., Alex Iantaffi, Jeremy A. Grey, and Walter Bockting. 2012. “A Review of the Content and Format of Transgender-Related Webpages.” *Health Communication* 27 (5): 457–66.
- Huttunen, Aira, and Terttu Kortelainen. 2021. “Meaning-Making on Gender: Deeply Meaningful Information in a Significant Life Change Among Transgender People.” *Journal of the Association for Information Science and Technology* 72 (7): 799–810.
- Jiang, Jialun Aaron, Charles Kiene, Skyler Middler, Jed R. Brubaker, and Casey



- Fiesler. 2019. "Moderation Challenges in Voice-Based Online Communities on Discord." *Proceedings of the ACM on Human-Computer Interaction* 3 (CSCW): 1–23.
- Keys, Os, Burren Peil, Rua M. Williams, and Katta Spiel. 2020. "Reimagining (Women's) Health: HCI, Gender, and Essentialised Embodiment." *TOCHI* 27 (4): 1–42.
- Kitzie, Vanessa. 2018. "'I Pretended to Be a Boy on the Internet': Navigating Affordances and Constraints of Social Networking Sites and Search Engines for LGBTQ+ Identity Work." *First Monday* 23 (7).
- Kitzie, Vanessa. 2019. "'That Looks Like Me or Something I Can Do': Affordances and Constraints in the Online Identity Work of US LGBTQ+ Millennials." *Journal of the Association for Information Science and Technology* 70 (12): 1340–51.
- Lau, Annie, and Trevor M. Y. Kwok. 2009. "Social Features in Online Communities for Healthcare Consumers—A Review." In *International Conference on Online Communities and Social Computing*, 682–89. Berlin: Springer.
- Lijadi, Anastasia Aldelina, and Gertina Johanna Van Schalkwyk. 2015. "Online Facebook Focus Group Research of Hard-to-Reach Participants." *International Journal of Qualitative Methods* 14 (5).
- MacLeod, Haley, Kim Oakes, Danika Geisler, Kay Connelly, and Katie Siek. 2015. "Rare World: Towards Technology for Rare Diseases." In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, 1145–54.
- MacLeod, Haley, Ben Jelen, Annu Prabhakar, Lora Oehlberg, Katie Siek, and Kay Connelly. 2017. "A Guide to Using Asynchronous Remote Communities (ARC) for Researching Distributed Populations." *EAI Endorsed Transactions on Pervasive Health and Technology* 3 (11): e4-e4.
- Malatino, Hil. 2019. "Future Fatigue: Trans Intimacies and Trans Presents (or How to Survive the Interregnum)." *TSQ: Transgender Studies Quarterly* 6 (4): 635–58.
- Malatino, Hil. 2020. *Trans Care*. Minneapolis: University of Minnesota Press.
- Maloney-Krichmar, Diane, and Jenny Preece. 2005. "A Multilevel Analysis of Sociability, Usability, and Community Dynamics in an Online Health Community." *ACM Transactions on Computer-Human Interaction (TOCHI)* 12 (2): 201–32.
- Metoyer, Ronald A., Tee S. Chuanromanee, Gina M. Girgis, Qiyu Zhi, and Eleanor C. Kinyon. 2020. "Supporting Storytelling with Evidence in Holistic Review Processes: A Participatory Design Approach." *Proceedings of the ACM on Human-Computer Interaction* 4 (CSCW1): 1–24.
- Miller, Brandon. 2017. "YouTube as Educator: A Content Analysis of Issues, Themes, and the Educational Value of Transgender-Created Online Videos." *Social Media + Society* 3 (2). <https://doi.org/10.1177/2056305117716271>.
- Miller, Ryan A. 2017. "'My Voice Is Definitely Strongest in Online Communities': Students Using Social Media for Queer and Disability Identity-Making." *Journal of College Student Development* 58 (4): 509–25.
- Nolan, Ian T., Grace Poudrier, Catherine C. Motosko, Tiffany E. Cook, Whitney Saia, M. David Gothard, and Alexes Hazen. 2020. "Continued Barriers to Top Surgery Among Transgender Men." *Plastic and Reconstructive Surgery* 145 (2): 464e–465e.
- Oakley, Abigail. 2016. "Disturbing Hegemonic Discourse: Nonbinary Gender and Sexual Orientation Labeling on Tumblr." *Social Media + Society* 2 (3).

- Ortega-Williams, Anna. 2021. "Organizing as 'Collective-Self' Care Among African American Youth in Precarious Times." *Journal of African American Studies* 25 (1): 3–21.
- Piepzna-Samarasinha, Leah Lakshmi. 2018. *Care Work: Dreaming Disability Justice*. Vancouver: Arsenal Pulp Press.
- Pohjanen, Aira Maria, and Terttu Anna Maarit Kortelainen. 2016. "Transgender Information Behaviour." *Journal of Documentation* 72 (1): 172–90.
- Pols, Jeannette. 2014. "Knowing Patients: Turning Patient Knowledge into Science." *Science, Technology, & Human Values* 39 (1): 73–97.
- Poudrier, Grace, Ian T. Nolan, Tiffany E. Cook, Whitney Saia, Catherine C. Motosko, John T. Stranix, Jennifer E. Thomson, M. David Gothard, and Alexes Hazen. 2019. "Assessing Quality of Life and Patient-Reported Satisfaction with Masculinizing Top Surgery: A Mixed-Methods Descriptive Survey Study." *Plastic and Reconstructive Surgery* 143 (1): 272–79.
- Prabhakar, Annu Sible, Lucia Guerra-Reyes, Vanessa M. Kleinschmidt, Ben Jelen, Haley MacLeod, Kay Connelly, and Katie A. Siek. 2017. "Investigating the Suitability of the Asynchronous, Remote, Community-Based Method for Pregnant and New Mothers." In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, 4924–34.
- Prinsloo, Jeanne. 2011. "Negotiating Transgender Identities on the Internet—A South African Study." *Agenda* 25 (4): 30–41.
- Psihopaidas, Demetrios. 2017. "Intimate Standards: Medical Knowledge and Self-Making in Digital Transgender Groups." *Sexualities* 20 (4): 412–27.
- Puckett, Jae A., Peter Cleary, Kinton Rossman, Brian Mustanski, and Michael E. Newcomb. 2018. "Barriers to Gender-Affirming Care for Transgender and Gender Nonconforming Individuals." *Sexuality Research and Social Policy* 15 (1): 48–59.
- Rachlin, Katherine. 2018. "Medical Transition Without Social Transition: Expanding Options for Privately Gendered Bodies." *TSQ: Transgender Studies Quarterly* 5 (2): 228–44.
- Raun, Tobias. 2015. "Archiving the Wonders of Testosterone via YouTube." *TSQ: Transgender Studies Quarterly* 2 (4): 701–9.
- Rawson, K. J. 2014. "Transgender Worldmaking in Cyberspace: Historical Activism on the Internet." *QED: A Journal in GLBTQ Worldmaking* 1 (2): 38–60.
- Redmiles, Elissa M., Jessica Bodford, and Lindsay Blackwell. 2019. "‘I Just Want to Feel Safe’: A Diary Study of Safety Perceptions on Social Media." In *Proceedings of the International AAAI Conference on Web and Social Media*, vol. 13, 405–16.
- Reisner, Sari L., Renee K. Randazzo, Jaclyn M. White Hughto, Sarah Peitzmeier, L. Zachary DuBois, Dana J. Pardee, Elliot Marrow, Sarah McLean, and Jennifer Potter. 2018. "Sensitive Health Topics with Underserved Patient Populations: Methodological Considerations for Online Focus Group Discussions." *Qualitative Health Research* 28 (10): 1658–73.
- Rodgers, Shelly, and Qimei Chen. 2005. "Internet Community Group Participation: Psychosocial Benefits for Women with Breast Cancer." *Journal of Computer-Mediated Communication* 10 (4): jcmc1047.
- Rupert, Douglas J., Jennifer Gard Read, Jacqueline B. Amoozegar, Rebecca R.

- Moultrie, Olivia M. Taylor, Amie C. O'Donoghue, and Helen W. Sullivan. 2016. "Peer-Generated Health Information: The Role of Online Communities in Patient and Caregiver Health Decisions." *Journal of Health Communication* 21 (11): 1187–97.
- Scheuerman, Morgan Klaus, Stacy M. Branham, and Foad Hamidi. 2018. "Safe Spaces and Safe Places: Unpacking Technology-Mediated Experiences of Safety and Harm with Transgender People." *Proceedings of the ACM on Human-Computer Interaction* 2 (CSCW): 1–27.
- Schönbauer, Sarah Maria. 2020. "'From Bench to Stage': How Life Scientists' Leisure Groups Build Collective Self-Care." *Science as Culture* 29 (4): 524–45.
- Selkie, Ellen, Victoria Adkins, Ellie Masters, Anita Bajpai, and Daniel Shumer. 2020. "Transgender Adolescents' Uses of Social Media for Social Support." *Journal of Adolescent Health* 66 (3): 275–80.
- shuster, stef m. 2021. *Trans Medicine: The Emergence and Practice of Treating Gender*. New York: New York Press.
- Simpson, Ellen, and Bryan Semaan. 2021. "For You, or For 'You'? Everyday LGBTQ+ Encounters with TikTok." *Proceedings of the ACM on Human-Computer Interaction* 4 (CSCW3): 1–34.
- Spade, Dean. 2020. *Mutual Aid: Building Solidarity During This Crisis (and the Next)*. Brooklyn, NY: Verso Books.
- Stone, Sandy. 2013. "The Empire Strikes Back: A Posttranssexual Manifesto." In *The Transgender Studies Reader*, 221–35. New York: Routledge.
- Strauss, Anselm L. 1987. *Qualitative Analysis for Social Scientists*. New York: Cambridge University Press.
- Stryker, Susan. 2017. *Transgender History*. New York: Seal Press.
- Visser, Laura M., Inge L. Bleijenbergh, Yvonne W. M. Benschop, Allard C. R. Van Riel, and Bastiaan R. Bloem. 2016. "Do Online Communities Change Power Processes in Healthcare? Using Case Studies to Examine the Use of Online Health Communities by Patients with Parkinson's Disease." *BMJ Open* 6 (11): e012110.
- Vistisen, Peter, and Thessa Jensen. 2021. "Social Affordances and Ethical Challenges in Mediated Collaborative Platforms." In *EthiComp 2021: [New] Normal Technology Ethics: Moving Technology Ethics at the Forefront of Society, Organisations and Governments*, 17–25. Universidad de La Rioja.
- Walker, Ashley Marie, and Michael Ann DeVito. 2020. "'More Gay' Fits in Better: Intra-community Power Dynamics and Harms in Online LGBTQ+ Spaces." In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, 1–15.
- Wilson, Stelios C., Shane D. Morrison, Lavinia Anzai, Jonathan P. Massie, Grace Poudrier, Catherine C. Motosko, and Alexes Hazen. 2018. "Masculinizing Top Surgery: A Systematic Review of Techniques and Outcomes." *Annals of Plastic Surgery* 80 (6): 679–83.
- Yeadon-Lee, Tracey. 2016. "What's the Story? Exploring Online Narratives of Non-Binary Gender Identities." *The International Journal of Interdisciplinary Social and Community Studies* 11 (2): 19–34.

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